

Kentucky CSHCN 2015 Maternal Child & Health Application/2013 Annual Report

Each year, states are required to submit an Application and Annual Report for Federal funds for their Maternal and Child Health Services Title V Block Grants. While the Kentucky Department for Public Health is the Kentucky grantee, federal guidance requires that at least 30% of Title V funding be allocated for services for Children and Youth with Special Health Care Needs (CYSHCN). Services for CYSHCN are administered in Kentucky by the Commission for Children with Special Health Care Needs (CCSHCN) and include providing and promoting family-centered, community-based, coordinated care (including care coordination services) for CYSHCN and facilitating the development of community-based systems of services for CYSHCN and their families. This document summarizes the draft application & report of the portion of the Application and Annual Report pertaining to CYSHCN.

Section I Public Input

- CSHCN seeks input from staff, supervisors, management, and stakeholders in the creation of the Application and Annual Report. Additionally, CSHCN makes special efforts to reach out to families of CYSHCN – including their representatives on the Youth Advisory Council and Parent Advisory Council.
- CSHCN wants to hear your comments! If you have any comments on this document, or want more information on the 2015 Maternal Child & Health Services Title V Block Grant application, please respond electronically via the link on our website, or by visiting: <http://www.surveymonkey.com/s/2015MCH> If you do not have access to a computer, or have any questions, you may contact Mike Weinrauch at (800) 232-1160, ext. 2026.

Section II Needs Assessment Summary

- Every 5 years, a formal needs assessment is completed; the most recent needs assessment was submitted in 2010. With input from community stakeholders, CSHCN determined that the 2 priority needs over the 5 year period would be addressing obesity and provision of transition services for CYSHCN. State Performance Measures 7 and 8 (see below) describe Kentucky's plan for addressing these priorities. CSHCN has convened workgroups for each priority need, and these workgroups meet regularly to monitor progress.
- CSHCN is continually looking at its services to see what can be improved or fine-tuned. Through information and feedback received through clinic comment cards for children and youth enrolled in CSHCN, and the consumer comment line, and through the National Survey of Children with Special Health Care Needs (NSCSHCN), CSHCN is able to identify strengths, as well as needs and gaps, and to assess the current environment.

Section III Overview

Note: The following sections contain original narratives submitted in 2010, as well as the annual update from the prior year (marked */2014/*), which follow the original submissions. This year's updates appear in **bold** and *italics* and are marked */2015/*.

▪ A – Overview

CCSHCN dates back to 1924 when it was created by the State Legislature in response to a request from the Rotary Club to provide treatment to children with orthopedic conditions through itinerant clinics across the state. The focus on community-based systems of care continues today. In addition to being a direct services provider, CSHCN assumes a leadership role in assuring state and local systems of care for children and youth with special health care needs (CYSHCN) and in promoting a broader definition of health for CYSHCN and their families as defined by the World Health Organization: "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity."

CCSHCN has a strong commitment to the inclusion of families and family support. This was acknowledged and enhanced in 2009, when CSHCN was awarded the Family to Family Health Information Center grant, which provides for developing family partnerships throughout the state, so families may act as mentors for each other. As a national leader in developing systems to support the transition of CYSHCN to adulthood, KY became the first state to develop a Title V performance measure for transition to adulthood in 1997. This initiative has continued to be an area of growth and

continues to evolve to meet the needs of our children beginning at enrollment, regardless of age.

CCSHCN continues to focus on the expanded need to serve children statewide, including an increased emphasis on population-based services. The KY Early Hearing Detection and Intervention (EHDI) program consistently reports the screening of over 99% of KY newborns with referrals for diagnostic screening given to all children reported to have a risk factor for hearing loss. The program is currently focused on obtaining the follow-up diagnostic testing results for the newborns who have been identified as at-risk for hearing loss.

/2014/ The adjustment to Medicaid managed care implementation continues. Statewide, five MCOs now cover Medicaid recipients. Barriers experienced by families include denials of preauthorization for necessary services and holes in service delivery. Challenges around locating MCO-enrolled providers for CYSHCN reported in 2013 continue. We continue to guide and advocate for CYSHCN on an individual basis and by participating in ongoing dialogue with MCOs to reach solutions. In regards to the Affordable Care Act, the abrupt end to referrals to the Pre-Existing Condition Insurance Plan presents a challenge, not unique to Kentucky, with the financing of care for those (especially those between 18-21) with chronic conditions who do not qualify for insurance and cannot afford to participate in the state's high-risk pool.

As a result of a revised Memorandum of Understanding with the child welfare agency, nurses statewide have assumed the role of convener of Individual Health Plan meetings for medically fragile children in foster care. The medically fragile home visiting and foster care nurse consultant programs continue.

A strategic plan has been assembled, with a July 1st implementation date. Themes include collaboration, marketing and outreach, improvement of services and identification of service gaps, telemedicine, and provider recruitment/retention.

D70 grant activities continue; the partnership with Children's Hospital Foundation has produced a series of webinars available to the public on both adolescent topics and parent topics. Additionally, the Morehead office has developed an individualized discharge summary template that will be piloted with physicians in the area to aid in timely and appropriate discharge to adult health care.

As part of an effort to move down the MCH pyramid, agency leadership is identifying offsite and low-census clinics where there are no longer barriers to care and asking whether direct gap-filling services are necessary and whether those services should be transitioned to community providers. The agency's intention is to provide services to previously unserved CYSHCN. As a part of the effort to become more well-known to families of CYSHCN, an outreach and communication plan is under development.//2014//

/2015/ Within the structure of a Strategic Plan, CCSHCN continues to deliberately expand services to previously un-enrolled CYSHCN on multiple fronts, through initiatives such as developing new partnerships to meet the needs of underserved populations such as those with Autism Spectrum Disorders and Muscular Dystrophy (see agency coordination narrative, below), revising eligibility criteria for the Youth Advisory Council (which has resulted in the participation of new members who have previously been unaffiliated with CCSHCN), becoming a part of a larger effort to form a statewide network of volunteers (or, "kynectors") who help Kentuckians in their areas become educated about and enrolled in insurance coverage through the Kentucky Health Benefit Exchange, and serving in formal supportive roles for various groups such as those in the child welfare system and those families of CYSHCN who are of Limited English Proficiency. Further, the agency is examining the eligibility criteria for the provision of direct services, and expanding or contracting to meet current needs.

As such outreach continues, the need to more accurately measure data beyond

the provision of direct services is critical. CCSHCN is examining traditional data collection efforts, for the purposes of developing more accurate internal management information and to guide future program development; as well as inform future block grant reporting. In past annual reports, CCSHCN has substituted consumer- and agency-generated data (mostly from the patient base) in place of national survey data, in order to measure year-to-year changes in progress or lack of progress toward indicators, and to connect results to programs. However, this approach suggests a clinical focus, and pertains to a subpopulation of the larger population of CYSHCN in Kentucky. CCSHCN will be working with a Graduate Student Epidemiology Program (GSEP) student to analyze current efforts and to assist in building data capacity. Further, agency staff is working with DPH staff to pull information from available data sources beyond what is currently being routinely reviewed. While performance measure data reporting processes have remained the same for this year for consistency, the agency is awaiting further guidance as far as the MCH 3.0 transformation and continuing with ongoing Needs Assessment activities.//2015//

▪ B – Agency Capacity

Despite challenging economic times, the Commission maintains a strong commitment to enhancing the quality of life for KY's children with special health care needs through direct service, leadership, education and collaboration. Through 12 regional offices across the state, direct medical services are provided to children with defined medical conditions, both congenital and acquired. Locations of regional offices and list of conditions treated by CCSHCN can be found at: <http://chfs.ky.gov/ccshcn>. Through diverse staff (nurses, therapists, nutritionists, transition coordinator, social workers, medical director, audiologists, parent liaisons, for example), CCSHCN provides family-centered, community-based care by sending treatment teams including nurses and pediatric specialty physicians to clinic sites throughout the state. Clinics for specific complex conditions that require multi-physician treatment teams are held only in Louisville and Lexington due to availability and coordination of providers.

Throughout the state, alignment with universities and partnerships with other agencies (e.g. Shriner's & Kosair hospitals, Norton Healthcare) support access-to-care issues, lend capacity to the agency, and promote non-duplication of services. Families in need receive financial support to assist with travel and/or lodging in order to attend clinics or receive hospital services. CCSHCN maintains a local provider network through contracts with approximately 600 contract physicians and surgeons. Other medical and ancillary services (e.g. therapists, pharmacists, audiologists) are available through contracts with local community providers. CCSHCN also contracts with foreign and sign-language interpretative services to assure effective communication that is easily understood by families of diverse cultures including those with hearing impairments. These services are available in each Commission region.

CCSHCN has a Memorandum of Agreement with UK to operate and staff a Medical Home for Coordinated Pediatrics, designed to provide primary health care and other services to the foster care population. CCSHCN also has a Memorandum of Understanding with the Department for Community Based Services (DCBS) to provide nursing consultative services to children in the foster care system. Consultation to the DCBS social workers and foster care families includes discussion of medical issues, interpreting medical records and reports, assuring updated portable health summaries and enhancing care coordination of all services to improve health outcomes for this population.

CCSHCN supports and encourages process improvement with the recommendations of parents of and CYSHCN. In addition to two parent consultants who are on staff, the agency coordinates a Youth Advisory Council which provides an opportunity for CYSHCN to collaborate with other youth, discuss pertinent issues, express needs to CCSHCN staff and become empowered in the management of their own health care. As well, the Parent Advisory Council and provides the same opportunity for parents of children and youth with special health care needs. Council members are provided financial support with their travel, meals, and lodging.

In 2009, CCSHCN received a Family to Family Health Information Center (F2F) grant. This funding provides parent consultants the ability to coordinate family partnerships throughout the state. Although the partnerships will be voluntary, CCSHCN will provide financial support with travel, childcare, meals, and lodging as needed. This new family mentor-matching program will provide a gateway for information-sharing between families, and will allow them to maximize their existing community resources. CCSHCN also received a grant for the KY Infants Sound Start initiative to support the same, as well as support for the KY chapter of Hands and Voices-an organization for families and children who are deaf or hard of hearing.

CCSHCN continues to expand the capacity of its health information system to fully support the core functions of public health as relates to CYSHCN: to assure early identification and screening leading to diagnosis, treatment, and access to community-based systems of care; to provide comprehensive care coordination with the context of the medical home; to identify and eliminate disparities in health status outcomes; and to support program accountability through the collection, analysis, and reporting of data and progress in meeting performance targets. The electronic patient data collection system (CUP) allows staff to enter patient information directly into a system designed to serve as an electronic medical record. Information pertaining to the demographic, diagnostic, treatment, medication, insurance, and transition history for each patient is maintained in a password-protected system on a secure network. This system is designed with future expansion and accommodation of agency needs in mind. Most recently, enhancements were made which enable audiological follow-up results to be electronically transferred, whereas, in the past, agency staff was manually entering each submitted follow-up report. This will improve the collection of follow-up audiological information; thus reducing the number of children who are lost to follow-up.

CCSHCN is experiencing an expansion of audiology services, and is becoming the preferred pediatric audiology specialist in the state. CCSHCN has more pediatric audiologists than any other public or private agency, provides technical assistance to and participates in partnerships with school systems, serves as a state and national consultant on EHDI issues, and is moving towards cochlear implant support services due to the absence of other providers in this arena.

/2014/ Due to the level of need and shortage of specialty care providers outside of major urban areas, CCSHCN is studying the opportunity for telemedicine to become part of the array of services. The agency is in the exploration stage. Following demonstrations and testing a pilot is scheduled with the Owensboro neurology clinic during 2013. Expansion into other areas will occur. The initiative will use existing videoconferencing equipment. The agency continues to experiment with technology; currently, tablets are available for use in the clinical environment.

Given the shortage of pediatric audiology providers in some districts, hearing aid-only clinics for children who receive otology services from non-contracted ENT physicians in their communities have been established. By assisting CYSHCN to obtain hearing aids at Medicaid cost, families are able to afford appropriate amplification. Since children with permanent hearing loss typically require replacement hearing aids every 3-5 years, the financial barrier related to this component of the intervention process is alleviated.

Cognizant of the need for data to drive decision-making, CCSHCN is working to obtain and analyze Medicaid claims data for the EHDI program, in an effort to reduce loss to follow-up. The agency hopes to expand research of Medicaid claims data into other area so that special targeting may be conducted (for example high users of Medicaid who may need care coordination).

A Maternal and Child Health training for the workforce has been initiated, in order to educate staff and connect job tasks with the overall Title V program. The agency used resources available on the MCH Navigator website to develop the training, and intends to use the site not only for the orientation training, but also throughout the year to inform and build the skills of staff. Through a partnership with a local entity, training on cultural competence is being planned agency-wide, and will include the advisory councils, F2Fs,

and all CSHCN staff. CSHCN has begun work on program standards for all areas against which the agency may measure progress. Additionally, agency social workers have, for the first time, convened a quarterly meeting in order for these professionals to discuss common issues, strategies, and areas for quality improvement.

An emphasis is being placed on productive labor, especially with regard to therapy staff -- in order to be able to see more CYSHCN and control no-shows.//2014//

/2015/ CCHSCN's telemedicine project has been underway for 9 months. As of March, 2014, staff and providers have conducted 17 successful tele-neurology clinics in 8 different sites and with 6 different physicians. The result is that waiting lists have decreased, access to care has improved, and cost per patient is competitive. Patients report satisfaction at a rate of 98.9%. CSHCN is currently exploring other pediatric sub-specialty clinics for introducing care via telemedicine.

The agency continues to work on health care practice standards. Examples include case management, medical care, nursing care and clinic services (record keeping, staffing and confidentiality) standards of care. CSHCN is creating standards around the recently-developed AMCHP systems of care standards framework.

CSHCN continues to reach previously unserved CYSHCN by providing enabling services through collaboration with the University of Louisville and the Muscular Dystrophy Association. Clinics are held at the University of Louisville, and CSHCN nursing staff provide case management, as well as social services and nutrition service as needed.

In Eastern Kentucky, a direct services clinic has been transitioned from CSHCN to the Gill Heart Institute. This arrangement prevents duplication of services, combines CSHCN patients with patients affiliated with the University of Kentucky, and allows for the provision of enabling services upon referral.

In Louisville, CSHCN continues to expand services to children in the foster care system via a partnership between the Department for Community Based Services and the Home of the Innocents' Open Arms Children's Health programs. Open Arms provides ready access to primary medical, dental, and behavioral health care to children in foster care. Services include clinics, audiology and vision services, as well as pharmacy service for prescriptions and over-the-counter medications and medical supplies. CSHCN provides general social work care coordination services as a member of an integrated team. The agency's other foster care support programs (including a medical home clinic in the Lexington area, statewide foster home nurse visitation for medically fragile children, and co-located nurse consultants available to child welfare workers statewide) continue to serve this important population of CYSHCN.

Outreach activities to Spanish-speaking families of CYSHCN include Spanish-speaking support groups, as well as outreach and education.

As is mentioned in the overview, CSHCN has a need for and an interest in improving capacity for gathering and analyzing relevant data to guide program management. Participation in the GSEP program is a first step. Through partnership with DPH staff, leadership is identifying additional sources of information and developing a plan for its use. As public health services increase, the needs exists to collect data on the provision of services beyond clinical. CSHCN is looking at capturing information not currently recorded in the patient information system. One effort includes the possible analysis of F2F data regarding non-CSHCN consumers. //2015//

▪ C – Organizational Structure

CSHCN operates under a streamlined organizational structure, pursuant to a 2009

reorganization. The agency employs an Executive Director; a, Medical Director; 2 Division Directors with one Assistant Director; and a full administrative, support, clinical, and augmentative staff throughout 12 regional offices.

The Division of Administrative Services provides intake, personnel, provider contracting, billing, financial reporting, and health information services. The Division of Clinical and Augmentative Services provides medical and foster care support services, including clinical operations. This division is organized in an East-West structure for clinical programs, and all therapeutic, transition, parent consultant, and audiology services through the Early Hearing Detection and Intervention program are organized under separate managers.

CCSHCN's Executive Director and Division Directors are appointed by the Governor, as are members of the Board of Commissioners and the Hemophilia Advisory Committee – who are stakeholders and interested community members and professionals. The Board of Commissioners provides oversight and approval of the Executive Director's actions. The Board meets quarterly with the Executive Director and senior management to review program status, consult and advise on programmatic concerns, and take voting action as required. The Medical Director recruits and recommends physicians to serve in clinics and on the Medical Advisory Committee, and the Executive Director, with approval of the Board of Commissioners, appoints members to the Medical Advisory Committee. The Early Hearing Detection and Intervention (EHDI) program also operates under the oversight of the EHDI Advisory Board.

In addition to two contracted parent consultants, the agency incorporates public parent and youth involvement in decisions that impact programs and service delivery. The Parent Advisory Council and Youth Advisory Council are comprised of individuals throughout the state (not just families with children enrolled in CCSHCN services) who hold an interest in children and youths with special health care needs (CYSHCN). Each Council meets quarterly at CCSHCN's Louisville office (or via videoconference) to discuss pertinent issues, provide training and give input on how CCSHCN can better serve Kentucky families with CYSHCN.

/2014/Gov. Beshear appointed Eugene Foster, Ph.D., to the position of Deputy Director from 11/13/12. Among other initiatives, the Deputy Director assists with the direction of agency efforts in the areas of strategic planning, program development, employee MCH training and development, and infrastructure-building.//2014//

/2015/ [No update.] //2015

▪ D – Other Maternal & Child Health (MCH) Capacity

In 2008, the Commonwealth of Kentucky experienced widespread retirement as a result of a designated retirement window. The Commission for Children with Special Health Care Needs (CCSHCN) was impacted as well.

Executive Director - Rebecca Cecil, R. Ph., served as CCSHCN's Executive Director from 2008 to 2010. Ms. Cecil served as CCSHCN's Director of Health and Development immediately prior to her appointment. [Her position was open from 9/1/10 through 9/1/11, at which time she was replaced by Jackie Richardson.]

Medical Director - Richard McChane, MD, has served as CCSHCN's Medical Director since March, 2007. Dr. McChane is also the Medical Director of the Home of the Innocents (a private child caring facility serving children with special needs in Louisville), serves as a developmental pediatrician at the University of Louisville Weisskopf Child Evaluation Center, and is a faculty member with the University of Louisville School of Medicine - Department of Pediatrics.

Director of the Division of Administrative Services - Shelley Meredith has served as director of this division since October 2008. Ms. Meredith has over 25 years experience with state government, over 20 of which have been with the Cabinet for Health and Family Services in the health care arena. Ms. Meredith played a key role in the

establishment and development of the CSHCN's health information system and electronic medical record and is now responsible for managing all the operational functions of CSHCN including budgets, contracts, purchasing, accounts payable and receivable, health information and technology, personnel, and grant reporting. Ms. Meredith is a Certified Public Accountant and 1985 graduate of the University of Kentucky with a BS in Accounting and a minor in Economics.

Director of Clinical & Augmentative Services - Anne Swinford has served as director of this division since 2005. Ms. Swinford's previous experience includes the provision of direct speech and language services to the special needs population, and served as the Acting Part C Coordinator and supervisor of Kentucky's early intervention program (First Steps). Ms. Swinford has over 25 years experience with special needs populations, including 17 in Kentucky's Cabinet for Health and Family Services. Ms. Swinford is a graduate of Brescia University and Purdue University, where she earned a BA in Speech and Hearing and a MS in Speech Pathology.

Director of Nursing – Karen Rundall has served in this role since 2009. Ms. Rundall has over 22 years of experience as a registered nurse providing pediatric care for children with special needs, including 9 years at CSHCN as a care coordinator and nurse service administrator. Ms. Rundall is a certified case manager (CCM) and a graduate of Jefferson Community College (ADN) and Bellarmine University (BSN), both of which have contracted with her to teach pediatric clinical experience at Kosair Children's Hospital. She also holds an MSN in Healthcare Leadership and Management from Western Governor's University.

Title V MCH Block Grant Coordinator - Mike Weinrauch serves as CSHCN's Title V coordinator. Other areas of focus include technical assistance with foster care support programs, social work with the bleeding disorder population, guidance to staff on brokering community resources, and general policy analysis/program evaluation. Prior to employment with CSHCN, Mr. Weinrauch served in Kentucky's child welfare & adult protective services agency as a field worker/supervisor and administrator at the regional and state levels. Mr. Weinrauch is a graduate of the University of Vermont (BA), the University of Kentucky (MSW), and the University of Louisville (MPA).

/2013/ Effective 9/1/2011, Jackie Richardson was appointed Executive Director. Ms. Richardson served 18 years with the Louisville Metro Government in various roles. Her career encompasses experience as an Internal Auditor, Business Manager, Chief Financial Officer and most recently 4 years serving as the Chief of Staff for the Louisville Metro Department of Public Health and Wellness. Mrs. Richardson possesses a Masters in Business Administration and a certification as a Professional in Human Resources.//2013//

/2014/ Deputy Director - Dr. Eugene Foster has over 25 years of executive leadership experience in children's services. He has served as President & CEO of several nonprofit agencies and is a former Undersecretary for Children & Family Services for the Commonwealth of Kentucky. Dr. Foster holds three graduate degrees in psychology and special education including a doctorate from Boston University. He is a regular presenter at state and national conferences concerned with best practices in children and family services. A licensed psychologist, he is an adjunct faculty member in the Department of Educational & Counseling Psychology at the University of Louisville where he has taught for over 10 years.

CSHCN maintains a workforce of 160 employees (including grant-funded and part-time), with 30 in central office/administrative positions and the remainder in regional offices across the state. //2014//

/2015/ Richard McChane has resigned as Medical Director and Judy Theriot has been appointed to this position as of 7/1/2013.

Medical Director – Judith Ann Theriot, MD, CPE attended medical school at the University of Louisville (U of L) then went on to complete her Pediatric residency and a chief resident year before joining the faculty at U of L. Dr. Theriot served as

the director of the General Pediatrics Clinical Research Unit (for two years) and the medical director of the Children and Youth Project; a multidisciplinary primary care clinic serving the inner-city high risk children of Louisville Kentucky (for 9 years) prior to this appointment. Dr. Theriot is a certified physician executive indicating advanced training and education in medical management and is a professor of Pediatrics at U of L.

Anne Swinford, Director of Clinical & Augmentative Services, has retired and no appointment has yet been made as to a successor.

Shelley Meredith, Director of the Division of Administrative Services, has retired and Janaki Kannan has been appointed to this position as of 3/1/2014.

Director of the Division of Administrative and Financial Services - Janaki Kannan has about 15 years of experience in various roles, of which 12 years are with governmental agencies. Her career encompasses roles such as Project Accountant, Financial Officer, Consultant and Business Manager. Ms. Kannan has been a Certified Public Accountant since 2006, holds a Bachelor's degree with major in Accounting and a Fellowship of Cost and Executive Accountant.//2015//

▪ E – State Agency Coordination

CCSHCN has a Memorandum of Agreement (MOA) with the Department for Medicaid Services that enables the agency to provide services for Medicaid eligible children enrolled for Title V/CYSHCN services. This agreement assures that services are provided in accordance with the Title XIX State Plan and EPSDT special services as required by OBRA 89.

CCSHCN also operates under a Memorandum of Understanding (MOU) with the Department for Community Based Services (DCBS) and is providing nursing consultative services in 8 of the 9 DCBS regions for children in the foster care system. This program was initiated in February 2005 to provide services for children who are medically fragile. It was expanded statewide in July 2006 to include the entire foster care population. The Nurse Consultants who work with this program provide consultation to the DCBS social workers and foster care families on medical issues, interpret medical records and reports, assure updated portable health summaries and enhance care coordination of all services. In November, 2007, it was further expanded in a collaborative effort with the University of Kentucky to open (via a separate Memorandum of Agreement) the Medical Home for Coordinated Pediatrics in the Lexington office, which provides primary care services to children in foster care in the central region of the state.

The Early Hearing Detection and Intervention (EHDI) program maintains many relationships in the administration of Kentucky's legislatively mandated newborn hearing screening program. In addition to the partnerships with the state's birthing hospitals, the program collaborates with the Commission on the Deaf and Hard of Hearing and the Kentucky chapter of Hands and Voices. Since 2006, a partnership with Vital Statistics has allowed the program to receive newborn hearing screening results for every child born in Kentucky electronically through the KY-CHILD database. Ongoing efforts at this time include work to expand online data transmission to allow community audiologists and early interventionists to electronically transmit diagnostic assessment results and to the EHDI program. New efforts are focused on working with Part C leaders to further expand Early Intervention services that more effectively meet the specific needs of newborns diagnosed with permanent hearing loss. In March 2009, Governor Beshear signed HB 5 which requires audiology diagnostic sites who wish to be included as approved centers for pediatric audiological testing to agree to meet specific requirements, including best practice standards and reporting to the EHDI program.

An agency partnership with Home of the Innocents (a private child caring agency providing hospital-like and "home away from home" environments for medically fragile children) allows Louisville therapeutic staff (PT, OT, SLP) to reside and provide services

at the Home of the Innocents facility. This arrangement allows CCSHCN patients and staff to utilize the advantages of a new facility, with state-of-the-art equipment, that is closer to the downtown area & medical complexes.

Memoranda of Agreements are maintained with the University of Kentucky and the University of Louisville to provide Hemophilia Treatment Centers covering the entire state's bleeding disorder population CCSHCN also provides assessments for the state's Disability Determinations Services division on behalf of the Social Security Administration for residents of Kentucky.

Currently, CCSHCN is working towards Memoranda of Agreement with First Steps to provide audiological services and to improve and streamline interpretation services. CCSHCN collaborates with the Kentucky Council on Developmental Disabilities (KCDD). The mission of the Kentucky Council on Developmental Disabilities is to create change through visionary leadership and advocacy so that people have choices and control over their own lives.

CCSHCN maintains numerous additional relationships with other state agencies. Programs with which our agency collaborates include: local schools, Office of Vocational Rehabilitation, Special Needs Adoption Program, the Kentucky Community & Technical College System, local health departments, Family Resource Youth Service Centers, Regional Interagency Transition Teams (RITT), State Early Childhood Transition Committee, KIDS NOW, State Interagency Council on Services to Youths with Severe Emotional Disabilities, and the state Child Fatality Review Program. Agency association with these entities allows us to further develop goals for the agency, provide community training, streamline services for children with special health care needs in their community and schools, educate, as well as prepare children for the transition into adulthood.

/2014/ CCSHCN is partnering with the Kentucky Autism Training Center to develop training for nursing staff, and participating in a statewide autism workgroup tasked with initiating a statewide strategy of addressing the needs of children with autism. CCSHCN offices are being modified where possible to accommodate children with autism. Since so many CYSHCN access the mental health system, CCSHCN is participating on the Child Behavioral Health Reform workgroup which seeks to expand access to quality services. The agency's executive director interacts with commissioners and department heads of other human services agencies regularly in the interest of better serving children with physical and behavioral health issues.

CCSHCN is providing screening equipment to First Steps (Part C Early Intervention); the goal is to have equipment in each of the 15 points of entry within 3 years.//2014//

/2015/ The newly-established Kentucky Advisory Council for Autism Spectrum Disorders, which is charged with developing and coordinating the state's system of care for persons with ASD, has been administratively attached to CCSHCN. The Advisory Council will provide a central location for the collection, dissemination and coordination of information regarding services and supports for Kentucky citizens on the Autism Spectrum across the lifespan. The Advisory Council will be responsible for coordinating current efforts that cross multiple government, university and private sector programs. In addition, it is charged with creating and supporting the necessary infrastructure to promote greater collaboration and coordination among both private and public service providers. The agency is exploring other ways to address the needs of this underserved population including assessment and medical home services.

CCSHCN has followed through on the plan to place screening equipment in each of the state's 15 First Steps (Part C Early Intervention) points of entry.

Kentucky was chosen as one of 8 states to participate in an AMCHP Action Learning Collaborative towards the goal of taking a leadership role in transitioning CYSHCN to Medicaid Managed Care Arrangements. The team includes a parent, a pediatrician, a Medicaid representative, and the Title V

	<p>CYSHCN Director.</p> <p><i>CCSHCN has signed an MOU with the KY River District Health Department. This agreement enables CCSHCN to disclose protected health information on infants who referred on their newborn hearing screening and are at risk for loss to follow up (LTF). A protocol has been established whereby WIC records will be utilized to locate and contact these families to schedule warranted follow up hearing tests. A strategy has been developed to document all efforts and use the experience in this pilot program to encourage other health departments to partner with CCSHCN in our efforts to reduce LTF. To enhance the collaborative relationship with the KY River District Health Department and to promote the mission of periodic hearing testing throughout childhood, the agency has requested grant funding to purchase Otoacoustic Emissions (OAE) hearing screening equipment for use by the 7 counties in the KY River District. CCSHCN staff will provide training and KY River District has agreed to provide hearing screening test results to CCSHCN for inclusion in the EHDI database.//2015//</i></p>
<p>Section IV Priorities, Performance and Program Activities</p>	<ul style="list-style-type: none"> ▪ National Performance Measures (NPMs) are measurements of results or achievements on specific outcomes. There are 18 common NPMs that all states report on yearly. ▪ State Performance Measures (SPMs) are additional measures selected by Kentucky based on identified priorities and our own unique needs. There are 8 Kentucky-specific SPMs. ▪ CCSHCN has responsibility for reporting on 6 NPMs and 2 SPMs, which are detailed in the sections below.
<p>National Performance Measure 2:</p> <p>The % of CSHCN age 0-18 years whose families partner in decision making at all levels and are satisfied with the services they receive</p>	<p>(Data derived by averaging responses to 2 questions on CCSHCN clinic comment cards, 1 regarding customer satisfaction and 1 regarding partnership)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 96.8% ▪ Last year's indicator: 96.9% <p>Last Year's Accomplishments</p> <p>KY CCSHCN recognizes the importance of family-centered care and strives to ensure that the perspective of families informs the provision of health care services to CYSHCN. Through care coordination, CCSHCN staff assist and enable CYSHCN to obtain family-centered, culturally-sensitive, developmentally-appropriate services. Staff actively engage in a partnership with families and providers to individualize care, provide support, and obtain the best possible outcomes. As children grow older, they take on a more active role in their own care.</p> <p>To measure the effectiveness of this collaboration and the direct care experience, the agency continued to use a comment card protocol in all onsite clinics. The comment cards provide timely input from families on an ongoing basis. The "mini-survey" is comprised of 6 questions (intentionally kept brief to encourage participation), but two separate questions measure satisfaction and listening – a key element of partnership. The resulting numbers are averaged to obtain the annual indicator for the Performance Measure. While the comment cards are anonymous, CCSHCN makes attempts to follow up on concerns when received. The high score remains comparable to those of previous years. The telemedicine project makes use of iPads to seek feedback from patients rather than paper-and-pencil surveys, and includes some additional questions regarding dimensions of satisfaction with the distance encounter. While Kentucky uses state-generated data to report progress on this National Performance Measure, CCSHCN notes that in the 2009/2010 National Survey of Children with Special Health Care Needs (NSCSHCN), Kentucky's families reported being partners in shared decision-making at a higher level (73.6%) than the national average (70.3%). This was also the case in the previous survey (2005/2006). Among CCSHCN enrollees, satisfaction and family participation remains high. Past the direct service level, CCSHCN's organizational structure continues to weave the voices of both parents and CYSHCN into the fabric of operations, so that families are involved in policy decisions that affect them, and are partners in decision-making. As the agency aspires to a workforce that helps elevate the role of families, CCSHCN professional interviews seek</p>

to screen all applicants with questions pertaining to family-centered care.

The Parent Advisory Council (PAC) and Youth Advisory Council (YAC) meet regularly, providing input on a variety of CSHCN matters and guidance for the KY Family to Family Health Information Centers (F2F). Eligibility for membership has been expanded to families of CYSHCN, as opposed to CSHCN enrollee families, and videoconferencing technology ensures a more geographically diverse group. Several members are able to attend meetings remotely. During the past year, a focus has been on educating members about services the agency offers, and key concepts of MCH. In turn, members are better-informed spokespeople and advocates who can outreach and advocate in their communities on issues of concern to the CYSHCN communities.

Family consultants attended multiple trainings and CSHCN staff participated in community events (e.g. Transition Fairs), partnering with professionals and parents and providing opportunities to take back information on available services to CSHCN patients, and to educate on CSHCN services available to the community. Family consultants played active roles on internal CSHCN work groups (e.g. Healthy Weight and Transition Action Plan) and external committees (e.g. Regional Interagency Transition Teams), lending a family perspective to policy-makers. Family consultants and “family scholars” attended the AMCHP/Family Voices conferences in order to acquire valuable information about national trends in maternal and child health topics and build relevant skills, and one of the F2F co-directors served as a mentor.

Under the guidance of F2F, parents provided one on one assistance to over 950 families during the reporting period to build the capacity of parents to advocate for their children’s needs. Data from nearly 300 impact calls reveals that the vast majority of those surveyed felt that the services received were very useful or extremely useful reported that the assistance/information/resources received was useful.

Current Activities

CSHCN evaluates services provided based on the clinic comment cards and refines as needed. It is the intention of the agency, through its policies and practices, to encourage families to discuss with care coordinators and contracted providers their child’s treatment and to provide a friendly environment in which it is easy to ask questions or raise concerns. Within the past year, care coordinators began assessing all clinic patients for the need for a formal nursing care plan developed with the family, and providing care coordination toward achieving identified goals.

Pursuant to the strategic planning goal of marketing and outreach, CSHCN’s Facebook page improves communication with current clients and provides an avenue to reach unserved CYSHCN through social media. Updates are more frequent than in years past (approximately 2-3 per week), and communication finally appears to be becoming more interactive. CSHCN has over 600 followers. Parents occasionally post to the page, and partner organizations have provided information and contacted CSHCN through the page seeking more information about services.

Current activities for F2F include expanding the network of parent consultants and youth mentors (over 75) and working with families and professionals directly to assist in problem-solving. Other Family to Family activities include the facilitation of periodic focus groups across the state to continue to gauge the needs of parents. F2F staff continue to send packets of informational resources to parents of newly-diagnosed infants with permanent hearing loss and make follow-up calls to offer assistance.

Plan for the Coming Year

CSHCN will continue to monitor results of surveys to ensure continued satisfaction among families of CYSHCN. CSHCN relies on its Board of Commissioners, PAC and YAC for guidance on how to best address the concerns of the special needs population. Board members are often parents of special needs children or practitioners with extensive expertise treating this population. Diversity allows CSHCN to receive feedback from a variety of external sources regarding the public perception of CSHCN programs.

	<p>CCSHCN's F2F continues to assist the network of support parents statewide who reach out to physicians and organizations to spread the word, recruit parents and youths for the PAC and YAC, assist individual families, and address the needs in regional areas. A goal is to positively impact the population of CYSHCN who do not currently receive services from CCSHCN.</p> <p>CCSHCN's Deputy Director continues to actively participate on AMCHP's Family and Youth Leadership Committee, a group responsible for setting activities to encourage engagement and empowerment, and to ensure a family perspective at the national level.</p>
<p>National Performance Measure 3:</p> <p>The % of CSHCN age 0-18 years who receive coordinated, ongoing, comprehensive care within a medical home</p>	<p>(Data derived by dividing CCSHCN patients 0-18 who identify a primary care physician by total population of CCSHCN patients 0-18)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 94.6% ▪ Last year's indicator: 93.9% <p>Last Year's Accomplishments</p> <p>As the medical home concept represents the standard of practice for CYSHCN, CCSHCN continued to work in partnership with those medical homes that exist, educate families about what a medical home is, and advocate for the development of medical homes in Kentucky's communities. During the reporting period, 70.7% of respondents to clinic comment card surveys indicated that CCSHCN had discussed with them the importance of a medical home. While CCSHCN traditionally reports annual indicators using state-generated data based on the number of CYSHCN with a primary care provider, it is noted that respondents to the 2009/2010 National Survey of Children with Special Health Care Needs ranked Kentucky near the top of the range across states in the medical home performance profile, and significantly above the national average in every category regarding the components of a medical home. However, the medical home performance profile remains 50.2%, signifying that Kentucky, like all other states, have more work to do. Further, disparities are noted between white, non-Hispanic CYSHCN and those CYSHCN who are Hispanic or Black in Kentucky in terms of the percent successfully achieving this outcome.</p> <p>The Pinkstaff Medical Home Clinic (MHC), a collaboration with the University of Kentucky and housed in the Lexington CCSHCN office, continues to provide primary care and care coordination for children involved with Kentucky's child welfare system. The clinic hosted over 1700 visits during the reporting year, and remains a well-established part of CCSHCN's array of services. A new partnership between the Home of the Innocents (a private child caring agency) and the Department for Community Based Services created a similar service in the Louisville area. CCSHCN social workers provide consultation and coordination in both clinics as part of an integrated care team.</p> <p>Agency staff participate with the Region 4 Genetics Collaborative which has a core mission to assure that CYSHCN receive comprehensive care in a medical home environment. Through collaboration with Region 4, informational handouts and guides have been obtained and incorporated in the family consultants' educational resources to ensure families become familiar with the principles of the medical home through a variety of methods. CYSHCN families are educated about what a medical home offers accessible, continuous, comprehensive, coordinated, compassionate, and culturally effective family centered care. Tip sheets are also available to provide guidance regarding choosing and working with a doctor, preparing for and participating in a doctor's appointment, what care coordination and culturally effective care look like, as well as continuous care while transitioning to adult care.</p> <p>Kentucky is completing work on a State Implementation/D70 grant which has as a goal of developing partnerships to ensure that CYSHCN have the resources and assistance needed for ongoing comprehensive care within a medical home. Impacts desired include outreach to previously unidentified CYSHCN, a self-sustaining comprehensive transition model, and access to resources that assist CYSHCN in becoming active partners who transition successfully into adult medical homes. A pilot begun in one CCSHCN regional office, in which care coordinators educate teens on skills needed to</p>

access adult health care, link them with a care provider, generate an individualized portable medical summary, attend the first appointment and follow up, has been presented to nurse administrators statewide and is in various stages of implementation in other regions.

Current Activities

Twelve CCSHCN offices throughout the state continue to provide culturally sensitive on-site multidisciplinary specialty clinics. Partnership with the child's medical home is vital. CCSHCN strives to ensure that all patients are active with a primary care physician by verifying that primary care services are received at each clinic encounter. If primary care is not identified, the clinical staff attempts to connect the family with an appropriate provider within its community. To ensure continuity of care, specialty clinic dictation and medical plans of care are shared with the patient's primary care physician (in accordance with HIPAA guidelines) after each clinic visit.

CCSHCN registered nurses and social workers provide comprehensive care coordination. These services include education, and developmentally appropriate transition services mindful of lifelong health goals and uninterrupted services into adulthood.

The CCSHCN foster care program continues to collaborate with the Department for Community Based Services (child welfare agency) to support the medical home model by ensuring that ongoing, preventative health services are addressed for the foster care population and those at risk of placement in foster care. Nurse consultants communicate with social services workers about the need for a medical home on consults. Nurse consultants also support the medical home concept by providing health education to youth, foster parents, and social service workers, as well as facilitate referrals to pediatric and specialty health care.

CCSHCN staff have implemented a revised assessment tool that focuses on youth aged 14 through 18 years, to assure access to resources that provide a continuous comprehensive system of health care into adulthood. Each patient receives a (recently revised and simplified) birthday letter at age 14, 16, and 18 that discusses future needs and invites the youth to contact his or her care coordinator to find services and to better prepare the youth for the transition into adult care systems. (Please see NPM 6 and SPM 8.)

Plan for the Coming Year

CCSHCN staff continue to work in partnership with families to ensure that CYSHCN have family-centered, medical home-type environments, and to work to coordinate services among providers when needed. A further emphasis on follow-up is planned on referrals, expanding partnerships (including looking into the feasibility of expanding medical home clinics to additional populations of CYSHCN, and continuing collaborations.

As standards of practice are established for care coordination, clinical staff will receive education to enhance and support their role in the medical home model.

One of the objectives of the State Implementation/D70 grant (Kentucky Integrated Services for CYSHCN, or "KISC") has been implementing the Medical Home concept. Staff are actively working on sustainability, particularly through community outreach to educate physicians who are unfamiliar with the Medical Home concept, and build skills in CYSHCN who are transitioning from pediatric care to adult health care. CCSHCN regional offices are working to build a network of adult physicians committed to providing care to transition age CYSHCN to improve the access of care as CYSHCN move to an adult health care model.

<p>National Performance Measure 4:</p> <p>The % of CSHCN age 0-18 years whose families have adequate private and/or public insurance to pay for the services they need</p>	<p>(Data derived by dividing CSHCN patients 0-18 with private or public insurance by total population of CSHCN patients 0-18)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 96.8% ▪ Last year's indicator: 96.3% <p>Last Year's Accomplishments</p> <p>CCSHCN continued to keep the uninsured rates for enrolled patients very low during this past year. Each person who referred for services was assessed for and assisted with obtaining available insurance options. The importance of catching the termination of private insurance coverage was highlighted as a breakdown in the continuity of coverage and several new detection methods and triggers were put into the business process in order to minimize the timeframe for a lapse in coverage. While the latest national data (2011/2012 NSCH) shows that Kentucky CYSHCN are insured at a rate slightly higher than non-CYSHCN, Kentucky CYSHCN are insured at a rate slightly below the national average for CYSHCN. Underinsurance as it relates to high deductible and co-insurance amounts remain a concern with the special health care needs population. These families often simply do not receive the supports they need to secure the prescribed interventions and do not have the additional financial resources, over and above the premium costs, to pay the rising costs required for treatment. As documented gaps in coverage have existed, which have the potential to cause significant financial hardship, CCSHCN strives to educate families about options and solutions. Kentucky has a state-run benefits exchange and expanded Medicaid.</p> <p>Upon learning of the ACA navigator program which was developed by the Office of Kentucky Health Benefits Exchange (KHBE), CCSHCN pursued inclusion as means to assist families during the open enrollment period (10/1/13-3/31/14) and beyond. CCSHCN parent peer consultants, social workers, and select regional office staff are part of the statewide network of "kynectors" – individuals from trusted organizations who have been trained and selected to help provide information and assistance for "kynect", the state-administered Health Benefits Exchange. An agency "in-person assister administrator at CCSHCN's central office oversees 27 kynectors based out of twelve regional offices. As of 3/1/14, there have been over 1300 direct consumer contacts, with nearly 300 applications being initiated with the assistance of CCSHCN kynectors. Further, the agency contracts with a trusted nonprofit, Patient Services, Inc., to provide insurance case management and premium assistance for those qualifying individuals with eligible conditions – currently, bleeding disorders and cystic fibrosis.</p> <p>While CCHSCN has worked with one of the existing MCOs in one state Medicaid region since its inception in 1997, expansion first to three other statewide entities and the subsequent two Medicaid expansion MCOs, has meant some changes in the way care is financed. Through discussions and an initial orientation period with the MCOs, CCSHCN was able to educate MCOs as to the services the agency provides, which has allowed for partnerships and integrated practices. For example, nursing assessments were developed to align documentation with the needs of the existing MCOs, and nursing care plans were created to demonstrate an individualized plan of care is developed in partnership with the patient and family to accomplish goals. Documentation of case management provided by CCSHCN nurses is shared with the MCOs to avoid duplication of service. The entrance of multiple MCOs has affected CYSHCN enrolled in multi-specialty clinics (such as craniofacial anomalies and cleft lip and palate), as not every provider is enrolled in every MCO network, and this has the potential to fracture the team approach when providers are substituted on to teams. An example of cooperation is CCSHCN's work with the dental administrator for 3 MCOS to create policy specifically for CYSHCN enrolled in craniofacial anomalies and cleft lip and palate clinics to go beyond a cookie-cutter once-in-a-lifetime orthodontia benefit and permit phased treatment.</p> <p>Another success was in negotiating with 2 MCOs to assure that no pre-authorization for therapy services would be required. For other MCOs which do require pre-authorizations, therapists are educated on consistently documenting medical necessity when requesting pre-authorizations on the front end. However, variability exists among</p>
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the MCOs in terms of the authorizations required for durable medical equipment such as ear molds and hearing aids. When facing such barriers to securing prescribed interventions, CSHCN staff and parent peer consultants continue their diligent effort to work with families to resolve issues on an individual basis (or obtain Medicaid waivers for needed services where appropriate). As staff navigate the learning curve, these efforts do have an opportunity cost, as professional staff time which could be devoted to providing more services is instead dedicated to such problem solving, and losses to the agency due to unpaid claims are incurred.

Current Activities

As sister agencies under the umbrella of the state's Cabinet for Health and Family Services, CSHCN and DMS leadership interact regularly in the interest of better serving their respective populations. While CSHCN had minimal involvement in the development of DMS's master agreement, the contract did make provisions for cost reporting as a way of ensuring reimbursement for the Title V agency. After the awarding of the contracts to the MCOs, CSHCN initiated discussions with the individual MCOs to offer an opportunity for the MCOs to learn about the Title V agency and its role with CYSHCN. Although CYSHCN are mentioned in the master agreements for the MCOs, none knew of the Title V agency's exact role and it is not known whether information presented has been shared beyond those at the table. As the Title V agency is a Medicaid provider, CSHCN leadership maintains working relationships with representatives from each of the MCOs and is able to renegotiate existing contracts accordingly.

At the time of writing, CSHCN leadership is planning to participate in AMCHP's Action Learning Collaborative for State Title V CYSHCN Directors and Teams. As a result, Kentucky's team hopes to become more proactive in identifying methods of capacity-building with the ultimate goal being able to ensure fair representation for and effectively advocate for and educate CYSHCN and their families on financing strategies for the care of CYSHCN. In particular, Kentucky could benefit from other state experiences with how Title V agencies can be actively involved and positively impact Medicaid negotiations during the next phase (i.e. contract process).

Plan for the Coming Year

Following the end of open enrollment, CSHCN will need to assess those who remain uninsured or underinsured, to develop a plan to address the remaining holes in coverage and determine how to identify and outreach to those who remain uninsured or without adequate coverage. This activity will align with the 5-year needs assessment for the Maternal and Children Block Grant and the agency's strategic goals of connecting with a larger population of children and youth with special health care needs by being more visible through outreach so that a wider population can be connected to and benefit from more community resources.

CSHCN will also need to evaluate how best to expand into other social media formats to inform and educate the public about their options for insurance coverage and how to best access those resources. The desired outcome is that more stakeholders will become more educated about solutions that may be available.

National Performance Measure 5:

The % of CSHCN age 0-18 years whose families report that community-based service systems are organized so they can use them easily

(Data derived by dividing CSHCN patients 0-18 with recorded note types of "general", "care coordination", "financial", "transitions", "clinic", or "intake" by total population of CSHCN patients 0-18)

- **This year's indicator: 96.3%**
- **Last year's indicator: 96%**

Last Year's Accomplishments

Despite the fact that ease of use of community based service systems represented a strength for the state in the previous needs assessment, results of the 2009/2010 National Survey of Children with Special Health Care Needs showed that 36.2% of Kentucky CYSHCN did not meet criteria for MCHB Outcome 5 – i.e., they reported difficulties or frustration in obtaining community based services that are easy to use. This represents a figure slightly above the national average of 34.9%. Though CSHCN

reports progress on this indicator with state data – specifically, information on coordinated services received by CYSHCN enrolled in the CSHCN program – it is apparent that national data merits deeper examination.

Kentucky's CSHCN clinical program fills a gap in direct health services by providing specialty clinics in regional offices across the state and recruiting a network of contracted providers who are willing to see and treat CYSHCN. Beyond the provision of medical services, though, CSHCN staff assist families of CYSHCN to navigate existing systems of care in many ways – through the care coordination of registered nurses, brokering of services by social workers, nursing consultation by staff outstationed in child welfare offices, and referrals/services provided by a variety of augmentative staff. In the service of developing community based systems of service, CSHCN staff and administration work to advance integrated care systems for CYSHCN through collaborations exploring interagency partnerships, expanding enabling services outside the clinical program, targeted outreach efforts to inform CYSHCN and their families, funding new projects through D70, and by maintaining intranet and internet sites designed to educate staff and families about community resources. CSHCN also maintains a Facebook site, which are used to provide information.

Family to Family Health Information Centers (F2Fs) represent a key strategy toward assisting with education, accessibility of services, and navigation of community based services. F2Fs continued to provide one on one family peer information sharing to educate as to how community based services are organized and how they can be accessed and/or financed. F2Fs also worked with those interested in improving the delivery of services by equipping them with the tools and information they needed to advocate for needed changes. In addition to guiding individual families to services through a network of parent mentors and youth volunteers, F2F worked with other entities (such as Kentucky Special Parent Involvement Network and the Kentucky Commission on the Deaf and Hard of Hearing) to increase their expertise in specific services and resources available and then disseminate information. Support parents have attended conferences, workshops, and school events throughout the state to disseminate information with families of CYSHCN, including those enrolled in CSHCN and those outside CSHCN.

As accessible transportation is a problem for some CYSHCN, the Youth Advisory Council developed a transportation tipsheet for dissemination by CSHCN staff.

CSHCN seeks to collaborate with other community partnerships to coordinate activities and service delivery. CSHCN staff continued to be actively involved in the Kentucky Interagency Transition Council for Persons with Disabilities and 11 Regional Interagency Transition Teams (RITTs) across the state. Participation in these and similar activities enable CSHCN to connect and share information with CYSHCN, their families, and other service providers. CSHCN strives to be a visible and relevant contributor to the local and state service systems and, to that end, last year participated in a variety of multidisciplinary groups, such as Community Collaborations for Children, Safe Kids Coalitions, District Early Intervention Councils, Special Education Cooperatives, and local committees that support area charities and resources for low-income residents. Partnerships have included "Operation Preparation" events, as well as transition fairs, and disability fairs.

Current Activities

It is a goal of CSHCN to ensure that all CYSHCN, not just CSHCN enrollees, have access to medical providers and the coordinated support services that they need. In accordance with the agency's strategic plan goals of collaboration and outreach, staff are building upon efforts to determine a path to better outreach to large concentrations of CYSHCN. Plans are underway for the agency to host "open houses" in both the eastern and western parts of the state in order to seek collaboration with service providers, hospitals, schools, and other groups in order to improve services and efficiency. At the same time, leadership, staff, and members of the PAC and YAC, are implementing a communications and marketing plan to address the lack of awareness of CSHCN services. The provision of "birthday bags" to hospitals for newborn continues.

Staff moves forward toward the objectives of the D70 grant, including partnerships to ensure CYSHCN outside CCSHCN have the resources and assistance needed for care and support.. Bridges to the Future (health care transition) and the outreach programs to Spanish-speaking families of CYSHCN (La Casita Center and Una Mano Amiga support groups), mark key partnerships. CCSHCN endeavors to provide infrastructure support to other service providers, in an attempt to integrate services in a way that makes them accessible to all, and connect CYSHCN with resources.

In addition to employing care coordinators, social workers, and family consultants who consult, advise, and refer families, CCSHCN maintains a dedicated consumer call line, through which enrollees or the public may be connected with a service or resource or be assisted with an issue. A dedicated line is also available for Spanish speakers.

Plan for the Coming Year

CCSHCN is considering adjusting data collection efforts to better measure ease of use of community based services for CYSHCN and to develop a more holistic indicator which ensures that all elements are considered (including universality, service accessibility, service value, and affordability). The end goal is to ensure that the service system provides what is most needed by families of CYSHCN, CCSHCN's GSEP project includes an in-depth examination of data collection efforts in the next five-year cycle, as well as close study of data available through the Data Resource Center and the National Center of Health Statistics.

CCSHCN's F2F will continue to work with families and seek their input on their needs and provide training to assist, and will develop additional materials that are easy for families to understand regarding how to navigate community based services.

As part of the agency transition plan (see SPM 8), CCSHCN will continue to work to improve how it acquaints adolescent patients and their family members with community based services to help make it easier for families to access these services.

As the recipient of a State Implementation Grant for Systems of Services for Children and Youth with Special Health Care Needs, CCSHCN has as objectives working with community partners and building relationships to minimize duplication of effort while improving outcomes for CYSHCN. CCSHCN continues to add providers to its network, especially in rural areas, while continuing to work with other partners to expand services to a wider base of CYSHCN than the agency has traditionally served. A focus will be on closing loops and evaluating services and referral patterns – and following up with families who did not qualify for ongoing services directly provided by CCSHCN, to ensure that they found and are accessing needed services.

CCSHCN's Foster Care Support program will continue to provide individualized assistance through case-specific consultations with child welfare staff, visits to "medically fragile" children in foster care, and primary care at the Medical Home for Coordinated Pediatrics. One goal of these programs is to make the health care system more navigable for CYSHCN in or at risk of state's care, child welfare workers and foster parents.

Efforts continue towards outreach and the recruitment/retention of providers, both items considered in the development of the agency's strategic planning. By the end of 2014, CCSHCN expects to have completed written recruitment and training plans for physicians, as well as identifying financial incentives feasible for physicians.

National Performance Measure 6:

The % of youth with special health care needs who received the services

(Data derived by averaging responses to 2 questions on CCSHCN clinic comment cards by youths or families of youths ages 13+, regarding work and independence, with a query of the CUP data system showing the percentage of CCSHCN patients 14-18 who have plans for an adult health care provider)

- **This year's indicator: 54.9 %**
- **Last year's indicator: 55.2%**

necessary to make transitions to all aspects of adult life, including health care, work, and independence

Last Year's Accomplishments

Possibly partially due to the reliance of a paper transition checklists during a short period while the patient information system was reengineered with a more interactive tool, the state-generated transition scores have declined, but improvement is noted in two of the three subscores (independence and job skills/education) not shown. The agency believes that the indicator decrease may be associated with the information system change, which occurred during FY 2013. CCSHCN is aware that Kentucky's score (37.1%) on the 2009/2010 National Survey of Children with Special Health Care Needs represents a decrease from the 2005/2006 survey score (42.8%), which places the state below the national average (40%). Through work on this NPM and SPM 8, CCSHCN has created a plan to increase agency capacity regarding transitions, a priority identified in the most recent needs assessment. Planning for coordinated services as CYSHCN move into adulthood is an integral element of the discussion CCSHCN initiates with youth and their families. Outside of clinics, CCSHCN outreaches to non-enrolled or previously unidentified CYSHCN to provide resources and support during this critical period through collaborations in activities such as Disability Mentoring Day and local and regional job fairs. Going forward, F2F staff may be able to track through the Salesforce database services provided to non-enrolled CYSHCN.

Updates to the transition checklist are intended to simplify the process and increase active patient and family participation in the discussion. Families are able to initiate the discussion, and the planning is more individualized and relevant to the CYSHCN's needs. In addition to the discussions that CCSHCN staff have with its patients, Kentucky's Family to Family (F2F) provide one on one assistance with families and professionals on transition issues. While CCSHCN and F2F staff engage in active partnerships with youth and families toward preparing for their own individual transitions, the agency simultaneously continues to promote the improvement of the very system that serves CYSHCN.

CCSHCN's D70 continues to develop community and state partnerships supporting the expansion of transition initiatives, including those targeted at previously unidentified CYSHCN. Specific deliverables include webinars, Journey to Adulthood binders, and an expanded nursing transition program (described in future plans, below).

Active involvement in the Kentucky Interagency Transition Council for Persons with Disabilities and the 11 Regional Interagency Transition Teams (RITT) across the state, which includes participating in transition information fairs, job/transition fairs & Disability Mentoring Day activities, assist CYSHCN to job shadow and explore employment. Being a part of these types of activities allows CCSHCN and F2F support parents to share information and resources and encourage CYSHCN and their families to pursue work and independence as an adult.

The CCSHCN Transition Administrator serves on the Board of Directors for the Center for Accessible Living. Independent Living Centers are important links for transitioning youth to post-secondary education, work and independence. The Transition Administrator brings back first-hand information to CCSHCN staff and can serve as a liaison between CCSHCN and this agency.

One of the best ways to find out what the needs are of young people is to ask them. In collaboration with the University of Kentucky Human Development Institute, conducted a one day youth forum which brought together a small group of young adults (ages 21 to 35 years old) with SHCN who have successfully transitioned from high school to the adult world. These young adults identified barriers to and opportunities for successful transition in all major areas: Education, Career, Relationships, Mobility & Transportation, Finances, Housing and Adult Healthcare. The next phase of this project, a peer support network, continues into the coming year (see below).

Current Activities

Transition planning begins early and follows a youth's developmental progress. The revised transition checklist, guides the process, with prompts for health skills and independence/school/work. Staff work with families to assess and document whether skills have been accomplished, are a work in progress, or a future expectation.

As a designated “disability service agency”, CSHCN provides voter registration services pursuant to the National Voter Registration Act. The agency has formalized procedures wherein all 18 year-old CYSHCN enrolled in clinical programs receive letters and voting forms upon application to the program, reapplication, and change of address. CSHCN staff are available to assist, and transmit forms to the appropriate county clerk for processing. As part of the transitions discussion, staff are prompted to discuss in greater detail voter registration information as a means to help educate CYSHCN about their right to vote.

CSHCN and F2F continue to work with families on transition issues and to make the process easier for families to understand. Transition services are addressed through one-on-one discussions with families enrolled in CSHCN programs, by collaborating with community partners, and encouraging participation from all members of the disability community.

CSHCN staff continue to look for ways to address transition needs of unidentified CYSHCN in their respective communities and participate in events such as information fairs with local school districts and a variety of other agencies. Similarly, CSHCN continues to partner with transition liaisons from the 9 state special education cooperatives.

Plan for the Coming Year

A project piloted in the Morehead office as part of D70 grant activities is in varying stages of replication in other regions. This initiative provides for expanded transition services, including portable medical summaries that provide a snapshot of where the youth is, developing a protocol to partner with youth to build the skills needed for transition to adult health care, outreach to adult providers to build their capacity, and assistance to YSHCN with locating medical homes.

With the assistance of the YAC and PAC, CSHCN continues to improve the CSHCN Facebook page, so that it can be used to effectively distribute information about transitions issues. The Transition Administrator and other CSHCN staff submit topical or resource information regularly when an item of interest to CYSHCN is identified.

CSHCN will continue to use the revised transition checklist on an individual basis, and continue to work with YAC, PAC, families, schools and other community partners to identify and address transition needs of CYSHCN during the coming year. To increase agency capacity, CSHCN is working to achieve the goals detailed in SPM 8. KISC will continue implementation through planned activities listed above as well as establishing the youth Peer-to-Peer Transition Support Network that would connect the young adults with special health care needs who have successfully transitioned to adulthood with younger youth with special health care needs who are in transition.

National Performance Measure 12:

The % of newborns who have been screened for hearing before hospital discharge

(Data derived by dividing the number of newborns receiving hearing screenings by the number of births during the year.)

- **This year's indicator: 96.7%**
- **Last year's indicator: 98.5%**

Last Year's Accomplishments

Continued collaboration with birthing hospitals has enabled Kentucky's EHDl program to maintain a 98% screening rate for newborns prior to hospital discharge. Hospital Scorecards have been developed and implemented, and in conjunction with annual hospital visits, have assisted CSHCN staff in holding hospitals accountable for timely submission and improved accuracy of data files, and in increasing the numbers of newborns who receive warranted follow up by age 3 months (82% FY 2013)

The CCHSCN information system (CUP) collects and reports unduplicated, individualized demographic data for all newborns and tracks progress through the three components of the EHDl process: Screening, Diagnosis, and Intervention. Feedback is provided to hospitals on a monthly, semiannual, and annual basis to improve hospital

hearing screening programs.

Continued efforts aimed at reducing Loss to Follow Up/Loss to Documentation (LTF/LTD) are having an impact. Eleven (of twelve) of the CSHCN district offices are now routinely providing infant ABRs – the preferred follow up diagnostic test for infants who refer on one or both ears on the newborn hearing screen. Revisions to the Audiology Resource list, with inclusion of 11 CSHCN District offices as “Level II” Centers (capable of providing comprehensive infant diagnostic testing) has resulted in a significant increase in hospital referrals to the agency from across the state. (514 direct referrals in FY 2012; 613 direct referrals in FY 2013).

A Memorandum of Agreement that was signed with the Kentucky River Health Department at the end of FY 13 to assist EHDI in locating infants who require warranted follow up but are LTF/LTD has already yielded dividends. Infants have been located using contact information gleaned from the WIC database and have received warranted follow up testing and intervention where indicated. To maintain and promote continued collaboration, funding for otoacoustic emissions (OAE) hearing screening equipment has been obtained and training and distribution of the equipment to the Kentucky River Health Department is planned FY 2014. Purchase of OAE screening devices and training and distribution to 15 Part C (First Steps) Point of Entry Offices has resulted in an increase of follow up results regarding infants and toddlers age 1 month-3 years, with 329 records received in 2013.

The LTF/LTD rate has improved from 21% in FY 12 to 18% for FY 13. While the agency did not meet the stated goal of reducing LTF/LTD to 17%, CSHCN is confident that several of the initiatives that were put in place in late FY 13 (e.g. a gas card initiative to reduce barriers to scheduling follow up associated with transportation costs; improved release of information processes) will reap benefits for the FY 2014 reporting year.

Current Activities

Enhancements in CUP have enabled the capture of pertinent information on infants who refer on the newborn hearing screening. Monthly reports that include newborn hearing screen test results, date of scheduled outpatient screen, and date of occurred screen, test results and provider/audiologist are used to establish baseline performance measures of community audiologists on the Audiology Resource List. In addition, infant follow up screen test results will be linked to newborn hearing screening to ascertain that audiologists follow best practices guidelines in the testing protocol they implement with infants referred to their practice. The availability of data regarding follow up test protocols and results enables CSHCN to more effectively hold providers accountable.

Quarterly reports from CUP lists any child with a diagnosis of unilateral hearing loss and provides pertinent information regarding degree of loss, use of amplification, date of last hearing test, and enrollment status in Early Intervention. The Kentucky support group Hands and Voices (for parents of infants and children who have been identified as deaf or hard of hearing) has met regularly and recently succeeded in becoming a state chapter of the National Hands and Voices Organization. CSHCN has collaborated with this group on the purchase and distribution to hospitals of “Loss and Found” videos to provide information and motivation to parents to follow through on warranted re screening for infants.

Plan for the Coming Year

Continued collaboration with birthing hospitals, including monthly email reports, technical support as requested and annual hospital scorecards to maintain our high initial screening rate is planned. However, in the next year, less time will be devoted to hospital visits in order to enable CSHCN staff to provide additional outreach to primary care physicians and Medical Homes. CSHCN will collaborate with state and national partners to implement or expand on a number of quality improvement initiatives aimed at reducing loss to follow up at each of these critical junctures: 1) between referral on UNHS and outpatient re-screen or diagnostic audiology and 2) between diagnosis of permanent hearing loss audiology and enrollment in early intervention.

Activities will include increasing the knowledge base of physicians and Medical Homes

	<p>regarding the impact of failed UNHS and the importance of ongoing monitoring of hearing throughout childhood to detect progressive, late onset or acquired hearing loss; reducing loss to follow up by building effective referral pathways for hospitals, physicians, health departments and Medical Homes; continuing work with Early Intervention providers to develop a more streamlined approach for the exchange of individually identifiable information regarding children with permanent hearing loss; improving services for children diagnosed with unilateral permanent hearing loss and improving the dissemination of statewide resources and supports for infants and children identified as deaf and hard of hearing and their families</p> <p>Streamlined follow up for infants requiring diagnostic audiology services and assurance that communication to the medical home and the EHDI database occurs in a timely manner is a primary goal for the upcoming year. CSHCN will improve the support available to parents of infants with newly identified hearing loss as they navigate new territory, through continued collaboration with Hands and Voices and by accessing assistance through F2F trained parent consultants. Finally, CSHCN will continue to work with our Early Intervention partners to implement strategies to improve data sharing between Part C First Steps and KY EHDI. The aim is to decrease our loss to follow up between UNHS and diagnostic audiology from 16% to less than 10%; and to reduce our loss to follow up between diagnosis of hearing loss and enrollment in early intervention by 4%.</p>
<p>State Performance Measure 7:</p> <p>Decreased % of children, ages 0-18, receiving CSHCN services, with a Body Mass Index (BMI) at or above the 85th percentile</p>	<p>(Data derived from the CUP information system, by dividing the number of children enrolled in CSHCN clinics whose Body Mass Index (BMI) is at or above 85th by the total number of children enrolled in CSHCN clinics whose BMI has been measured.)</p> <ul style="list-style-type: none"> ▪ This year's indicator: 35.8% ▪ Last year's indicator: 34.8% <p>Last Year's Accomplishments</p> <p>The annual indicator on SPM has increased 1% from the prior year, signifying that the percent of enrolled CYSHCN at or above the 85th percentile of BMI has gone up. During SFY 2013, over 87% of respondents (over 2100 families) who commented on clinic survey cards indicated that CSHCN staff discussed healthy eating and nutrition with them – up almost 20% from just 2 years ago. CSHCN feels that these sustained efforts represent agency commitment to the goal of reducing the risk of obesity among CYSHCN and the documented disparity between Kentucky CYSHCN and non-CYSHCN.</p> <p>CSHCN implemented its Healthy Weight Plan in May, 2011. The plan, aimed at reducing the proportion of CYSHCN who are at risk for being overweight or obese, and developed by a multidisciplinary and geographically diverse group of CSHCN and F2F staff from all levels of the organization, includes action in the areas of prevention, identification, and intervention/treatment.</p> <p>SFY 2013 marked the second full year of implementation of CSHCN's Healthy Weight initiative, including at its core, BMI tracking and individual health education, and the dissemination of health promotion materials to the CYSHCN population – a group who often find it more difficult to control weight and remain healthy. CSHCN attempts to reduce the risk factors by encouraging healthy eating and physical activity, and reduced “screen time” through a 5-2-1-0 campaign. The 5-2-1-0 model is statewide, although regional offices are encouraged to offer supplemental activities that may be able to engage their populations. Clinic environments are adorned with 5-2-1-0 posters and signs and offices stock trusted materials for patients (such as Chop-Chop magazine, articles from “Healthy & Fit”, “Healthy Favorites”, brochures from Jump Up and Go, and other media from sources like Bright Futures or “Let's Move”).</p> <p>CSHCN nurses were provided with talking points and “individualizable” letters to send with families of CYSHCN at or above the 85th percentile to their primary care physician or medical home – regarding treatment of obesity and obesity-related health problems. CSHCN has statewide coverage by registered dietitians housed in Morehead and Louisville, who are available to attend clinics in the Eastern and Western halves of the</p>

state, respectively, and to consult with CCSHCN staff. During the past year, staff dietitians provided training and consultation to each office regarding the Healthy Weight Plan and motivational interviewing with families. Following the training, staff reported feeling more comfortable discussing 5-2-10 with families of CYSHCN.

CCSHCN's Healthy Weight initiative maintains its materials on a page on the agency's intranet site, and messages or additional resources are shared with the public via the agency's Facebook social media site on a weekly basis.

Current Activities

Staff continue to calculate BMI in clinic, plot BMI percentile, and counsel families on the medical effects of childhood obesity when indicated. Staff refer to dietitians and health professionals/clinics trained in weight management when a consult is needed. Therapy staff engage patients individually in active physical activities per their needs. Given the lack of availability or infrequency of physical activity programs in many communities, the Healthy Weight Committee has considered the possibility of games or group activities to get patients more active while waiting for their appointments. Unfortunately, staffing, time, and space issues prohibit structured activity with groups in clinic/clinic waiting room settings.

Information system reports which identify patients with elevated BMIs who are coming to clinic in the next month are sent out to regional offices so that CCSHCN staff know to counsel these patients and their families at clinic. Many barriers exist; lack of time during appointments, family lack of readiness to make changes, or not accepting that overweight/obesity is a legitimate concern; families who are more concerned with their children's SHCN than they are about the risks of overweight or obesity. Staff make gentle efforts to overcome these barriers, and works with others to advance solutions to community concerns beyond the scope of the agency (for example, difficulty of finding or affording healthy food, or finding opportunities for physical activity). CCSHCN aims to participate in larger prevention efforts to address the obesity epidemic among Kentucky's CYSHCN population. Given the tradition of interagency partnership at CCSHCN, and the recognition of the societal nature of problem and that no one agency can solve the problem, many CCSHCN regions are participating in regional/local councils supporting the Partnership for a Fit Kentucky's obesity prevention initiatives.

Plan for the Coming Year

CCSHCN will continue to provide on-site nutrition consultation in each region - at least one clinic held in each regional office biannually. One on one consultation to patients in each region will continue to be provided as requested.

CCSHCN Dietitians will provide training to management staff in order to ensure that accurate height and weight measurements are being obtained. The training will discuss ways to accurately weigh and measure infants, children and patients that may be wheel chair bound or non-ambulatory. Dietitians will also provide an opportunity for staff to share challenges that they are facing in obtaining these measurements.

The practice of "tasking" the dietitians to make cold calls to at-risk patients has not met with a positive response. Alternate methods of intervention are being explored. The Healthy Weight committee prefers positive reinforcement strategies (for example, setting incremental goals and offering encouragement, sending "congratulations" letters to patients who were at or above 85% of BMI and subsequently fall below 85%) . The committee will analyze data available regarding how rates of overweight/obesity vary across clinics and age groups, and may recommend targeted outreach as indicated. Inclusion of healthy weight intervention as criteria in management audits of patient charts is an option which has been discussed. The committee will continue to meet regularly and evaluate the implementation of the plan and progress/lack of progress toward improved indicators on this SPM.

CCSHCN Dietitians are also in the process of developing tools to determine the value of nutrition interventions by looking at nutrition outcomes reviewing each objective of the individual healthy eating plan and recommending interventions to achieve the goal. Use

of retrospective data such as a care plan or a tool yet to be developed will evaluate each area. During the review, differences in anthropometrics will be identified and assessed, as well as behavior changes achieved by following the 5-2-1-0 healthy eating recommendations. This proposed tool will assist in using the best interventions in order to improve the quality of care for CSHCN patients.

State Performance Measure 8:

Degree to which CSHCN transition action plan is successfully completed and implemented

(Data derived by scoring the agency's progress/lack of progress toward implementing the agency's 13-point, 5-year Transition Action Plan – scoring on each item as follows: 0: activities have not yet begun; 1: activities have just begun; 2: activities are progressing; 3: activities are well-established; 4: activities are sustained)

[Below is a summary of the agency's Transition Action Plan, followed by a discussion:

1. Refine transition checklist for families and CYSHCN
2. Initiate tangible outreach to all CSHCN clients upon 14th, 16th, and 18th birthdays, including surveys/assessments of current levels of independence and preparation for school/work
3. Cultivate awareness on available community resources through public resource guide, intranet social service page for staff, community education events
4. Develop & implement systems to measure impact of transition efforts & policies
5. Establish and distribute training documents in a variety of settings for providers regarding their roles in the transition process
6. Increase visibility and active involvement of CSHCN Youth Advisory Committee
7. Revise agency procedures to conform to best practice consensus statement on health care transitions for CYSHCN
8. Initiate CSHCN procedure encouraging children's signature on medical forms starting at age 12
9. Provide support to CYSHCN regarding accommodations available to enable management of health care issues in educational settings
10. Create a written health care transition plan by age 12 for CSHCN children
11. Increase use of social media to reach and educate CYSHCN about pertinent health & transitions issues
12. Counsel & provide assistance with selection of adult health care providers, and encourage meetings with selected provider prior to discharge from CSHCN services.
13. Initiate transmittal of medical records (with release) to adult medical providers upon discharge.]

▪ **This year's indicator: 86.5%**

▪ **Last year's indicator: 75%**

Last Year's Accomplishments

During the past year, CSHCN's Transition Action Plan committee, oversaw continued implementation of the agency's 13-point, 5-year plan. The committee is chaired by the Transition Coordinator and includes members of both administrative management and field-level clinical services representatives. This year's total score on the plan of 45 out of a possible 52 points marks steady improvement over the previous year's score of 39 and the total score in the prior year of 33 out of a possible 52 points.

Update by plan number listed on detail sheets:

1. Activities are sustained. Full implementation was achieved in October, 2012.
2. Activities are sustained. Tangible outreach was implemented during a prior reporting period. Outreach letters continue, with a simplified message and more substantive content.
3. Activities are sustained. Aspects of this goal were completed previously (social service resource guides, Facebook page updates regarding community education events and topical transitions-related issues). A subcommittee has reviewed care coordinator resource binders, and supplemented the transition

checklist with electronic resources on the agency's internet page.

4. Activities are well-established. Clinic comment cards and revised transition checklists are used to measure the impact of transition efforts. The ability to measure and query specific data points to measure transition efforts is now part of the infrastructure of the agency's patient information system.
5. Activities are well-established. Under the D70 umbrella, . Kosair Children's Hospital has provided several trainings for providers in their geographic area. Further, the agency has partnered with the University of Kentucky Human Development Institute to provide webinars and developed brochures to distribute statewide. Deliverables from the D70 grant (such as Journey to Adulthood booklets) continue to be distributed.
6. Activities are sustained. The Youth Advisory Council (YAC) role has steadily increased as an advisory body. YAC youth participated in the agency's strategic planning process during the past year.
7. Activities are well-established. The committee feels that each element and the entire transition plan represent the agency's effort towards revised procedures to conform to the best practice consensus statement.
8. Activities are sustained. An updated agency policy was issued during a prior reporting year. Chart audits are conducted, using a tool incorporated in agency policy, to ensure that CYSHCN are signing their medical forms.
9. Activities are sustained. CCSHCN staff currently provides support to patients regarding accommodations available to enable management of healthcare issues in educational settings. Care coordinators document in their service notes activities they provide to support parents in managing healthcare issues in the school system. Family consultants and F2F support parents provide one-to-one and professional support to families of CYSHCN regarding management of issues in the educational setting.
10. Activities are progressing. As mentioned above, the revised transition checklist (a milestone-based guide that prompts staff to address transition points with CYSHCN and their families) is part of practice and the agency has also developed a individualized care plan portion of the electronic health record, of which transitions may be a component.
11. Activities are well-established. CCSHCN's social media presence includes an agency Facebook page which is growing in followers, and there has been a significant increase in activity and posting.
12. Activities are well-established. CCSHCN staff currently counsels patients, provides assistance with the selection of adult health care providers, and encourages meetings with the selected providers prior to discharge. A pilot initiative (see NPM 6) in one region is in various stages of implementation statewide.
13. Activities are sustained. CCSHCN currently initiates transmittal of medical records (with release) to adult medical providers upon discharge or identification, when the selected physician is known.

Current Activities

Implementation of the agency's revised patient transition checklist represents an important achievement toward enhancing CCSHCN's ability to better serve the needs of CYSHCN. The CCSHCN Transition Action Plan Committee continues to oversee the implementation of a variety of other transitions-related initiatives. Birthday letters, efforts toward increasing awareness of community resources, active involvement of the YAC, signatures of youths on medical forms, support to youths regarding accommodations available in educational settings, and the transmittal of medical records to adult medical providers are established elements of CCSHCN practice; however, other plan elements are in various states of progress (see above) and continue to receive agency attention.

Plans for the Coming Year

Please see above; CCSHCN continues to address the elements of the five-year plan, focusing on those items which are progressing, followed by those elements on which work has not yet begun.